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"WHAT'S NEW ABOUT NEW REPRODUCTIVE TECHNOLOGIES?"

A PRELIMINARY DISCUSSION PAPER

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This background paper was prepared for information purposes only for the Ontario Advisory Council on Women's Issues by Rona Achilles, Ph.D. In view of the rapidly changing technology in this field, we are aware that some of the information contained may be outdated by the time of publication.

COUNCIL MANDATE

The Ontario Advisory Council on Women's Issues was established at arms-length from the government in 1973, and is in a unique position to effectively challenge the government's direction and policies. Council's mandate is to advise the Ontario government on all matters pertaining to the achievement of economic, social and legal equality for women and without limiting the generality of the foregoing: to respond to requests from the Minister for advice, consultation; to hold public meetings with the purpose of stimulating public discussion and accessing the opinions of women; to identify the specific areas requiring the attention of government and to recommend legislation and program changes to the Minister Responsible for Women's Issues. There are 15 members, all of whom are appointed by Cabinet on a part-time basis. Meetings are held in Toronto and work on identified issues done through committees. Council brings a balance of women's views from across the Province to the government's attention.

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I. INTRODUCTION

In the past ten years a confusing new array of reproductive technologies have been developed and introduced to the practice of medicine. The birth of Louise Brown in Britain, in 1978, is generally understood as marking the beginning of a new era in reproductive technology. Louise Brown was the first child born conceived through in vitro fertilization; she is now almost ten years old. During these ten years there have been a number of other developments--some of them include highly sophisticated medical technology like in vitro fertilization, whereas others, like artificial insemination are not new procedures, nor are they very complicated but have come to public attention through the visibility of the more sophisticated technologies. Women are the primary consumers and in some instances experimental subjects of these technologies. The children conceived through these technologies are the completely unwitting experimental subjects.

The goal of this paper is to achieve two objectives:

1) the first is to assist the reader in understanding exactly what is occurring both technically and socially in the realm of some of these technologies. Technical literacy is a necessary prerequisite to comprehending the social and psychological ramifications of the procedures and eventually establishing practices and policies that will protect the health of the participants; and

2) the second goal is to provide specific information on what is occurring in Ontario. Ontario is a highly industrial and urban province and not surprisingly it is a centre for much of the new activities in new reproductive technologies in Canada.

Reproductive technology is a term which can describe any intervention in the reproductive process, including: birth control, sterilization, abortion, fetal monitoring, amniocentesis, or in vitro fertilization. There are, of course, tremendous differences among these technologies and it is useful to have a framework from which to view them. One method of categorizing the technologies is through their function in relation to new life, that is,

- those that **inhibit** new life,
- those that **monitor** new life, and
- those involved in the **creation** of new life.

Those technologies, for example, that inhibit new life include all forms of birth control, sterilization, and abortion. Those involved in the monitoring of new life include prenatal diagnostic techniques such as ultrasound, amniocentesis, and fetal monitoring. Technologies involved in the creation of new life are those concerned with artificial reproduction and include donor insemination, so-called "surrogate motherhood," arrangements[1] in vitro fertilization, embryo transfer, sperm banks, and the freezing of sperm, eggs or embryos.

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[1] "Surrogate motherhood" is the popular term used to describe these arrangements however the term "surrogate" does not accurately describe the woman's role who is the biological mother. This will be discussed in more detail later.

Donor insemination and "surrogate motherhood" arrangements do not involve sophisticated technology, nor are they medically or technically speaking new procedures. They are included in this discussion with other new reproductive technologies because they have emerged both in practice and to public view in the past ten years. It is important to emphasize that these procedures are extremely simple technically and it is their social ramifications that grant them significance in this discussion.

This typology provides a framework to organize discussion of new reproductive technologies. It is not meant to be comprehensive and in some instances technologies may overlap in different categories. For example, the advances in fetal surgery involve significant developments in new reproductive technologies and may have tremendous impact on women's status. Fetal surgery potentially distinguishes a fetus, still in utero, as a separate patient from the carrying mother. (Defined as a separate patient, the fetus potentially has separate rights.) Fetal surgery could be included in the category of monitoring of new life if we include in monitoring the "corrective" procedures that sometimes accompany them. A recent New York Times article, for example, describes a procedure which involves all three "types" of technologies. Women carrying multiple fetuses (in some cases up to eight--octuplets) were selectively aborting some of the fetuses in order for others to thrive. Physicians used ultrasound to guide a needle into the chest cavity of the one and a half inch fetuses that were to be aborted (Kolata, 1988).[2]

In addition, sex selection techniques do not fit neatly into this typology but are a significant realm of development in new reproductive technologies. New reproductive technologies, therefore, cover a spectrum of developments and are not a quantitative leap into advances that are unconnected to past or current reproductive technologies. Rather, they are an extension of technological developments and social trends already existent in our culture.

Reproductive technologies, therefore, are not new and have been an important vehicle for facilitating the improvement of the status of women. Although birth control that is both safe and effective has yet to be developed--a certain amount of control over women's fertility has been acquired. This report will focus on what are referred to as **new reproductive technologies**--those technologies which have developed, for the most part in the past decade and which many feminists are concerned may involve both a loss in status for women and dangerous health risks for all participants. The report is also limited to a consideration of two kinds of new reproductive technologies--those involved in the creation of new life--artificial reproduction--this is the major emphasis of the report and a more minor discussion of new prenatal diagnostic techniques. This first section of the report provides a description of the technologies and describes some of the social and psychological ramifications of their use.

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[2] The article points out the difficulties raised by a procedure such as this: 1) the children are wanted, 2) the difficulties posed by drawing the line, and by whom? and, 3) as stated succinctly by the author: "What is troubling is the prospect of a woman trying for years to become pregnant, undergoing enormous emotional strain and financial sacrifice to have a family of her own, and then ending up having to kill perfectly healthy fetuses (Kolata, 1988:1)."

II. ARTIFICIAL REPRODUCTION

A. Description of the Procedures

There are a variety of artificial reproduction technologies and their numbers increase rapidly as innovations, new methods, and knowledge develops. I will begin by describing those that are technically the most simple (usually involving artificial insemination) and moving towards those which are technically more complex (such as in vitro fertilization).

Artificial insemination is the simplest of all of the artificial reproductive technologies and it is also the oldest. Strictly speaking, artificial insemination is not a new reproductive technology since knowledge about the procedure has existed for over two hundred years in humans and has a much longer history with animals. As well as its lengthy history, the simplicity of the procedure also distinguishes it from other new reproductive technologies since it does not necessarily require sophisticated technical or medical procedures to be practiced or to be successful. It is included in this discussion for a number of reasons. Despite its lengthy history, the practice of artificial insemination came to public attention through the visibility of other artificial reproduction technologies so that it is really just in the past few years that, as a society, we have been aware of and begun to examine the implications of this procedure. Also, and most importantly, because artificial insemination is such a simple procedure it illustrates very clearly the importance of investigating the social and psycho-social ramifications of these practices. Even when the procedure is extremely 'low-tech' the social implications of the procedure can be enormous.

Artificial insemination is very simply a replacement for sexual intercourse. Sperm is obtained through masturbation and placed in the vaginal canal with some simple instrument similar to a turkey baster--hence the phrase 'turkey-baster babies'. The method of placing the semen in the reproductive tract is the only aspect of the procedure which can be described as "artificial". Conception, gestation, and birth take place as with any other pregnancy. The simplicity of the procedure creates the possibility of women inseminating themselves outside of clinical settings and without the assistance of physicians. The extent of self-insemination is unknown but there are women who are inseminating themselves in Canada and elsewhere in the world. A group of women in Windsor, Ontario set up a self-insemination service several years ago in which they assisted women in finding sperm donors. We can assume that most artificial insemination, however, does occur in clinical settings with the assistance of physicians and may involve other medical procedures.[3] There are several different types of artificial insemination which are defined according to the relationship of the participants to each other--these are: artificial insemination by husband, artificial insemination by donor, and artificial insemination combined. All three of these are used to solve an infertility problem on the part of a woman's male partner or to assist a woman getting pregnant who does not have a male reproductive partner. Another version of artificial insemination is "surrogate motherhood" arrangements. This is generally

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[3] Probably the majority of donor insemination does occur in medical settings, however, it is impossible to know about the incidence of the procedure either inside or outside of medical settings with any certainty.

used when infertility problems exist on the part of the woman in a couple.[4] "Surrogate motherhood" is, as the recent Baby 'M' case graphically demonstrated, an enormously problematic practice for women and will be dealt with separately in the next section.

Artificial insemination by husband poses no social dilemmas.[5] It is used when a man's sperm count is extremely low. The sperm is concentrated through a process of centrifugation and inserted mechanically into a woman's vaginal canal. In some instances, the sperm is placed inside the uterus (intrauterine insemination) to increase the chances of fertilization occurring. Intrauterine insemination may be used with any version of the procedure to increase success rates. Donor insemination (DI) is when a woman is inseminated with the sperm of a man who is not her partner or spouse. In clinical practice the sperm donor is usually anonymous--that is, unknown to the woman who is being inseminated. Outside of clinical settings when women practice self-insemination the donor may be known or unknown to the DI mother.[6] As well as donor anonymity, donor insemination is a procedure that is surrounded by secrecy. Keeping the donor insemination secret is generally advised by the medical community since openness about the procedure is perceived to cause a number of unnecessary problems. Furthermore, when practiced in clinical settings donor insemination may involve a number of other medical procedures designed to either ensure that the woman is fertile or to facilitate the process of fertilization. These may include: hysterosalpingograms,[7] endometrial biopsies, drugs to regulate her ovulation, and possibly drugs to sustain the pregnancy. Artificial insemination combined describes a procedure in which the sperm from a number of different men is pooled and a sample from that pool is used for insemination. This is used to disguise who the biological father of the child is if the procedure is successful. If the woman's partner's sperm is included in the pool, it may be used to encourage the idea that the subsequent child is biologically related to him--which is unlikely if he has infertility problems.

What is popularly referred to as ***"surrogate motherhood"*** is generally used by couples when the wife (or female partner) is infertile.[8] The husband's sperm is used to artificially inseminate a woman (the "surrogate") who agrees (contractually) to surrender the child at

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[4] But, in theory, could be used by anyone willing and able to persuade or hire a woman to bear a child for them.

[5] Artificial insemination by husband poses no social dilemmas in the sense that the practice conforms to cultural expectations of motherhood and fatherhood as biological as well as social.

[6] Unless otherwise indicated, discussion of donor insemination in this paper refers to donor insemination as practiced in clinical settings.

[7] A procedure in which dye is injected into the fallopian tubes and uterus to indicate, under x-ray, whether they are open or blocked.

[8] Wife and husband are used here in their broadest sense and not necessarily in their legal sense. In other words, a couple may not be married, but wife refers to the female partner and husband refers to the male partner. If the couple are not heterosexual, which they may not be, this will be stated explicitly. It is also possible that the recipient or contracting individual in a surrogate arrangement is single--male or female.

birth and is generally paid a fee for her role as a biological mother. "Surrogate motherhood" is actually a misnomer for this arrangement since "surrogate" implies "substitute" which the "surrogate" clearly is not. Rather than a substitute she is the biological mother of a child another woman (the social mother) will rear. Establishing an accurate and appropriate language to describe the social, biological, genetic, and legal relationships in "surrogacy" (as with all of these technologies) is an important, on-going, and unfinished project. Other possible terms include: breeder mother, carrier mother, pre-conception contractual mother, contractual breeder mother, etc. Since the different forms of "surrogacy" involve more complicated technology,[9] I will describe them in more detail later in the paper. In either case, however, it is important to point out that the woman carrying and bearing the child is the biological mother and not a "surrogate"--even though she may not be the woman who raises the child--and in the case of a donated egg may not be the genetic mother. In addition, depending upon the enforceability of the contract she may not be the legal mother. The "surrogates" are generally paid approximately $10,000. which, under most contracts, is paid only upon the delivery of a healthy newborn. For these reasons, despite the cumbersome language, "surrogate motherhood" will be referred to in the rest of this paper as "preconception agreements or contracts". The "surrogate" will be referred to as the contractual mother and the commissioning parent(s) as the contracting parents.[10]

Preconception contracts have been a much more visible and contentious procedure than any of the other NRT's. The recent case of 'Baby M'in New Jersey highlighted the dilemmas inherent in this controversial procedure. The contract required Whitehead to undergo amniocentesis (which she did against her own and her own doctor's wishes) and to abort the fetus if "defects" were diagnosed.[11] It also specified behaviours regarding lifestyle and diet during pregnancy. Mary Beth Whitehead, the contractual mother changed her mind about relinquishing her child, refused payment and fled to Florida. At the time of the contract, Whitehead was a full-time homemaker with two children and married to a sanitation worker. The Sterns, the contracting couple (a biochemist and a pediatrician) decided to take her to court. The judge's decision to give custody of the child to the contracting father and his wife set a legal precedent which favours the enforceability of preconception contracts for the production of children and which transparently also equated wealth with a better quality of parenting.

Mary Beth Whitehead appealed this decision and recently the decision of the higher court, the Supreme Court of New Jersey was reported. Chief Justice Robert Wilentz overturned

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[9] Such as, for example, a woman who carries another woman's genetic child through donated eggs or embryos.

[10] Another possibility is "purchasing" parents which emphasizes even more strongly the commercial nature of the transaction when money is involved. The weakness of using the language of contract to describe these relationships is that it might lend credence to the belief that these are legal contracts which, in fact, at this point they are not--at least not in Ontario. However, the project of creating an appropriate language could be the topic of another entire report.

[11] The issue of abortion was rejected by the judge as unenforceable.

all aspects of the earlier court's ruling with the exception of the custody decision. Although the custody decision was not overturned, Mary Beth Whitehead's parental rights were restored which will allow her to seek a new custody hearing. Most significantly, this ruling which will likely have impact in other jurisdictions rules that the contract between Whitehead and Stern was illegal because it violated the state's adoption laws concerning payment for a child. "'This is the sale of a child, or at the very least, the sale of a mother's right to her child, the only mitigating factor being that one of the purchasers is the father,' the court said."[12]

In vitro fertilization (IVF) is a much more invasive and technically sophisticated procedure than those already described. This is the procedure which is colloquially referred to as the "test-tube" baby technique. (An actual "test-tube" baby would be one in which the processes of conception and gestation would occur completely outside of a woman's body. The technical term for this is "ectogenesis" and, as far as is known, the technology for the complete process of supporting human life from conception to birth in an artificial womb is not yet available.) IVF involves several different steps or medical procedures which means that decision-making with this technology moves firmly into the hands of physicians. Linda Williams.[13] describes the process, in its simplest form, this way: "...IVF works by bypassing a woman's defective fallopian tubes. Her ovaries are hyper-stimulated with strong fertility drugs to produce multiple eggs which are surgically removed under general anesthetic. Her partner then produces a sperm sample by masturbation, and the eggs and sperm are combined in a glass dish. If fertilization occurs, the resulting human embryos are returned to the woman's uterus. She then must wait for approximately two weeks to see if these embryos have implanted and a pregnancy has begun."

As well as being more invasive and technically more sophisticated, IVF is described by participants as extremely stressful emotionally and in some cases financially costly.[14] The success rate, that is, the number of live births achieved from one cycle is extremely low. In other words, the failure rate is extremely high. It is difficult to get accurate statistics and practitioners report their success/failure rates in different ways which makes it difficult for the lay person to understand them. Estimates range from a 5% to a 20% success rate. It is not always clearly stated, however, whether the figures presented are:

- the success rate of that clinic or that of another clinic or clinics,

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[12] Robert Hanley, "Surrogate Deals For Mothers Held Illegal in New Jersey," The New York Times, February 4, 1988 p.1+ 14.

[13] Linda S. Williams (1987). Wanting Children Badly: An Exploratory Study of Parenthood Motivation in Couples Seeking In Vitro Fertilization. Doctoral dissertation (in progress). University of Toronto.

[14] In Ontario, O.H.I.P. covers the cost of IVF procedures. It is the only provincial health care system that does so. Even so, the procedure can be expensive for participants since they may have to pay for drugs, i.e. fertility drugs, which may cost several hundred dollars a month.

- the pregnancy rate--which is higher than the birth rate,
- what is meant by a pregnancy rate--i.e. ectopic pregnancies, elevated hormone levels or pregnancies which have terminated through miscarriage,
- the percentage of births per cycle or attempt, or after several attempts, or,
- the number of women who had children or the number of children born.

This latter point is significant since IVF has a very high rate of multiple births--to be discussed later.[15] (See Appendix A for a survey of the success rates of 12 Canadian clinics.)

As mentioned in the introduction, the first baby born through in vitro fertilization was Louise Brown in England in 1978. In other words, IVF as a successful procedure (in humans) has only been in existence for just under ten years. Despite this short history, clinics have sprung up all over the world and there are already twelve IVF clinics in Canada; five of these are in Ontario. All of the clinics report long waiting lists and there is little doubt that there is a solid "market" for IVF clinics among infertile couples.[16] An IVF practitioner contacted at University Hospital in London, Ontario stated they had between 600-800 couples on their waiting list. Pappert (1988a) reports that Ottawa Civic hospital which has just received its funding and has not yet opened already has a waiting list of two and a half years.

IVF was initially developed to bypass the problem of a woman with blocked fallopian tubes. More recently, it is being used to assist infertile couples when the male partner has a low sperm count. Similar to donor insemination, therefore, in this latter case--a woman who may be perfectly fertile becomes a patient. A significant difference between IVF and donor insemination, however, is that the medical procedures involved are much more invasive.

The procedure may vary in detail from clinic to clinic or from practitioner to practitioner and new developments are reported frequently in the media. The basic method, however, does not change and the following is a more detailed description of the steps and procedures involved. The first step is to produce, find, and remove eggs. This process begins on about the fifth day of a woman's menstrual cycle when she will begin taking the fertility drug Clomid to stimulate the development of egg follicles in the ovaries. Soon after this (approximately two days) she will begin receiving a daily injection of Perganol which is a fertility drug used to induce ovulation. Over a period of a week the Perganol

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[15] See, for example, Michael R. Soules' editorial in Fertility and Sterility, vol. 43, no. 4, April 1985, pp. 511-13, entitled "The in vitro fertilization pregnancy rate: let's be honest with one another."

[16] Again, statistics vary, but it is estimated that between 10-15% of Canadian couples experience infertility. Infertility is defined in Canada as one year of trying to get pregnant through unprotected intercourse.

may be increased depending upon how the woman's ovaries respond. Blood tests and ultrasound scans may be employed daily to assess and monitor the response of the ovaries. If the tests indicate that the woman's hormone levels are appropriate and there are sufficient egg follicles developing, between day 11 and day 14 of her menstrual cycle she will be admitted to the hospital for egg retrieval. After admission, a woman's hormone levels will continue to be monitored through blood tests and ultrasound. Once it is determined that ovulation is near the patient will receive an injection of HCG (human chorionic gonadoptropin) to induce ovulation within a certain time period (36 hours). This allows for the scheduling of surgery--the laparoscopy which is the egg collection phase. The surgery generally requires a general anesthetic and the usual routines such as fasting beforehand.

At any point in this process the patient may "succeed" or "fail" in her goal to achieve a pregnancy. If she "fails", for example, to ovulate at the right time for the laparoscopy then the rest of the procedure is "cancelled". The entire process therefore is extremely fragile and stressful. If the laparoscopy is successful--a laparoscopy is used to visualize the ovaries so that eggs can be aspirated from the egg follicles to remove the eggs--then the patient has successfully completed the first stage of the IVF procedure.

The second stage involves determining whether the eggs are healthy, discarding those which are not, incubating those which are (for a period of five to six hours) and then joining them in a culture dish with (usually) her husband's (or partner's) sperm. About 48 hours after the laparoscopy the healthy fertilized eggs are returned to the woman's uterus through a catheter--this is the third stage. The final phase is waiting to see if implantation occurs. Most women, as the low success rate indicates will not get this far, fewer still will achieve pregnancy, and even fewer will achieve a live birth. To increase the chances of implantation occurring, usually more than one fertilized egg is put into the uterus. When successful, this explains why IVF conceptions have a higher incidence of multiple births. This practice of transferring all of the fertilized eggs also resolves the problem of what to do with those which are not placed in the woman's uterus. In some cases, for example, they can be frozen and used at a later date. This, of course, raises a number of questions about who owns the embryos which are frozen. Can they, for example, be later thawed and used on another woman, or for research? Freezing of embryos occurs at at least one Ontario clinic and another hopes to begin an embryo freezing program in the near future.

Recently, a slightly more simplified version of IVF has been developed called **GIFT** which stands for ***Gamete Intra-fallopian Transfer.*** GIFT is similar to IVF in that

- ovulation is induced through a variety of fertility drugs,
- it utilizes ultrasound and monitoring of hormone levels to assess the development of the eggs, and
- a laparoscopy is used to remove the matured eggs.

Sperm obtained 2-3 hours before the laparoscopy is selected for its mobility and is concentrated for the transfer. The significant difference between IVF and GIFT occurs at this stage. Rather than attempting fertilization in vitro, the sperm and eggs are placed into a catheter which feeds directly into the woman's fallopian tubes during the laparoscopy.

This description has assumed that the recipient couple are using their own gametes (eggs and sperm) to achieve pregnancy. Another possibility is that the IVF procedure involves donor eggs or donor sperm. This would mean that the rearing parents would be different from the genetic parents--although this would not be socially visible since the woman would become pregnant and carry the child as in any other pregnancy. Two Ontario clinic report they will be using donor eggs in the near future.

A more recent development is called ***surrogate embryo transfer (SET)*** which combines artificial insemination with a later stage of IVF--embryo transfer. So far, this procedure is less common but may become more common in the near future.[17] Similar to IVF, SET is used with heterosexual couples when the problem of infertility is on the part of the woman. With this method, a woman, the "surrogate," is artificially inseminated with the sperm of (usually) the man who will rear the child. If successful, the fertilized egg is flushed (also called "lavage" or the "flushing" technique) from the surrogate's uterus and implanted in the uterus of the biological father's wife. At least one birth (probably more by the time of writing) has already occurred through this method. Although potentially less invasive than IVF, because it does not involve surgery, SET brings with it different risks and problems. If, for example, the flushing technique is not successful, the "surrogate" [18] risks an unwanted pregnancy and the decision to abort or carry to term.[19] As well as the risk of 'retaining' the pregnancy, the "surrogate" (donor) risks the possibility of pelvic infections or of an ectopic pregnancy--either one of which could result in her own infertility. [20] If a 'retained pregnancy' is carried to term conflicts would likely arise about who the child belongs to--as with other preconception contracts.

Finally, there is another possible use of IVF which was referred to in an earlier section on preconception contracts.This is the procedure which involves a woman carrying to term a child she is not genetically-related to--that is, acting solely as the ***gestational mother.*** The eggs may have been obtained from the woman who is going to rear the child or from a "donor" woman who will have no other biological or social relationship with the child. The most likely scenario is one in which the sperm and egg of a couple who want children

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[17] A conversation with an IVF physician about SET indicated that the success rate at this point in time is so low that he would not consider undertaking it.

[18] This is potentially an accurate use of the term "surrogate" since she acts as substitute or temporary gestational mother for a short period of time. She is, however, the genetic mother if her own eggs are utilized.

[19] This has in fact occurred and is referred to as a 'retained pregnancy'. The woman eventually aborted spontaneously avoiding future dilemmas. See, Bustillo, Maria, John Buster, Sydlee W. Cohen, et al. (1984) "Non-surgical ovum transfer as a treatment in infertile women." The Journal of the American Medical Association. vol. 251. no. 9. pp. 1171-1173.

[20] Howard W. Jones. (1983) Editorial. "Variations on a Theme". Journal of the American Medical Association. vol. 250. pp. 2182-3.

genetically linked to them (but the wife, for example, may not be able to carry [21] are fertilized in vitro and then implanted in the gestational mother. Similar to the first version of preconception contracts described above she will likely be subject to restrictions during the pregnancy and agree (contractually) to surrender the child at birth (most likely but not necessarily) to the genetic parents in exchange for a fee. As one IVF practitioner who I interviewed put it--"this is the best situation...one in which she is essentially a 'walking incubator'...that way she has no genetic material of her own and therefore the least attachment (My emphasis)".

B. Discussion

There are a number of social, psychological, and health issues raised by the use of artificial reproduction technologies. The following is a brief listing of some of these significant issues:

Infertility: One of the first issues raised by the use of these technologies is the problem of infertility itself. Infertility appears to be on the increase [22] although little is known about the causes for this proposed increase. Among the possible causes [23] are an increase in occupational health hazards, [24] environmental pollutants, the increase of sexually transmitted diseases, and the use of pharmaceutical drugs and devices such as DES [25] and the I.U.D. Other factors include an increase in the age of child-bearing and the reversal of decisions around sterilization such as vasectomies. It is, in fact, problematic to define exactly what constitutes infertility. Is, for example, a woman who decides not to bear a child due to diabetes, infertile? Elizabeth Stern, the contracting father's wife and adoptive mother of

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[21] For example, a woman who has had a hysterectomy but still has her ovaries and therefore could use her own eggs.

[22] Hard data to illustrate that infertility is actually on the increase is difficult to find. It may be that we are actually just more aware of it, but most analysts suggest that the prevalence is increasing.

[23] These are not listed in order of importance or prevalence.

[24] See, for example, Nancy Chernier, Reproductive Hazards at Work: Men, Women, and the Fertility Gamble. Ottawa: Canadian Advisory Council on the Status of Women, 1982. For an excellent discussion of reproductive health hazards and how fetal protection policies are influencing women's labour force participation in the U.S.--See, Carolyn Marshall, "Fetal Protection Policies. An Excuse for Workplace Hazard". The Nation.April 25, 1987, pp. 532-534 and Marianne Levitisky, "Protecting Workers from Reproductive Hazards". Canadian Journal of Women and the Law, vol. 1. no. 2. pp.488-497.

[25] DES stands for a drug named diethylstilbestrol which was given to pregnant women during the 1950's to prevent miscarriage. See, Anita Dereks, "Has the DES Lesson Been Learned?" Des Action Voice. Spring, 1986, pp. 1-2 & 4, for an interesting comparison of the introduction, original uses, and expansion of usage of DES and IVF.

'Baby M', was diagnosed as having a mild case of multiple sclerosis--is this, strictly speaking, infertility? The increase in knowledge about the genetic origins of disease, as well as the increase in genetic counselling is likely to have an impact on the use of artificial reproduction technologies. Clarification is required, however, to decide what constitutes infertility. Is there a difference between medical and social infertility and where is the line going to be drawn? These are questions raised by the use of these technologies and require public discussion and debate. In addition, research monies need to be directed toward understanding more about the causes of infertility so that the problem can be approached socially through preventative measures rather than individually through hi-tech solutions.

Cooper (1986) analyzed the costs of infertility treatments for 597 couples in a Nova Scotia clinic. She found that a substantial portion of the costs of infertility treatments arose from surgical procedures to treat endometriosis and tubal problems. Tubal problems caused by infection are largely preventable and Cooper points out that preventative measures could lead to large savings in infertility treatment costs. This is just one example of a preventable source of infertility--education and early treatment of sexually transmitted diseases.

The cost of IVF, the most expensive of the artificial reproduction techniques, is enormous. Pappert (1988a) cites the Ontario government as having spent seven million dollars in the past two years on four clinics. The total number of babies produced was 200 which means that each baby cost $35,000. In provinces where the cost is not covered by a medical plan, patients pay up to $5,200. Another unanticipated cost of IVF is the demand on perinatal units which occurs because so many births conceived through IVF are multiple births and usually premature (Surtees,1988).

Safety: Neither the short-term nor long-term effects of procedures and drugs used in artificial reproduction technologies are known. This includes the use of drugs such as Clomid and Perganol that are used to regulate and stimulate ovulation. Dereks (1986:4) states that "(T)he composition of Clomid is related chemically to DES, and mice treated with Clomid develop adenosis even more often than mice treated with DES." Ovarian cysts, which may rupture, are a known side effect of both Perganol and Clomid (Brozan, 1988). In terms of physiological effects there are several other procedures for which the short and long term effects are unknown such as the extensive use of ultrasound in IVF and the use of freezing techniques on eggs, sperm, and embryos. IVF also carries greater risks of abnormal fertilization, chromosomal aberrations from hormone-induced ovulation, and embryo abnormalities (Vanier Institute of the Family, 1987). There are also higher rates of miscarriage, premature delivery, and as mentioned previously IVF frequently involves multiple births.

In addition, little is known about the social and psychological effects of artificial reproduction technologies. In the most generous estimate, 80% of the women who go through IVF programmes do <u>not</u> go home with a baby. Participants describe themselves as becoming obsessed with the IVF programme and the project of acquiring a child may dominate their life. Some women withdraw from successful careers in order to fully devote themselves to the programme. When a woman or a couple decides to have a child, it is not unusual for disappointment to set in as months go by and a pregnancy is not achieved.

However, the experience of IVF participants is somewhat different since the stages of success and failure are visible to them through the technology (Williams, 1986).[26] They may become caught in a "treatment cycle" in which the hope and despair of trying to achieve pregnancy are exacerbated. To some extent, but less so, this particular issue is applicable to all of the techniques including donor insemination and pre-conception contracts. However, due to the extremely low success rate, psychological, financial, and emotional stress is extreme with IVF participants. For this reason, education and support groups are necessary to assist women participating in IVF programmes. There is no formalized support services in Toronto hospitals offering IVF.[27] Rather, women describe meeting in waiting rooms between procedures and providing support and encouragement to each other on an ad hoc rather than planned basis.[28]

In an attempt to provide an ethical framework for the use of new reproductive technologies, Newman (1986) suggests that long-term responsibility should outweigh the advantages of immediate outcome. "Focused as we are on immediate outcomes as a basic value, responsibility is not easily accepted for long-term effects of interventions (1986:288)." She cites the use of thalidomide and DES [29] as examples of short-term thinking which resulted in disastrous consequences. As well as an example of short-term thinking, Newman points to the example of DES as another example where a drug used therapeutically was expanded to preventative use.[30] She suggests scientific trials and careful observation of who is to truly gain from the use of particular drugs and technologies (including "personal or corporate benefit") as methods of assessing long-term effects.

Informed Consent: There are two main issues to consider in relation to informed consent. The first is that it is impossible to give truly informed consent concerning procedures about which so little is known--both in terms of physiological side effects and of the psycho-social consequences. Informed consent would mean that women participating in IVF

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[26] When a couple tries to conceive in the traditional manner and fails to achieve pregnancy all they know is that they did not achieve their goal. In Linda Williams' study of IVF participants she found that because the exact point of "failure" to achieve pregnancy was visible to the women that this was a psychological mechanism to keep them in the programmes. For example, if a woman got as far as successful fertilization of her eggs, she might feel that on her next attempt she would be more likely to achieve implantation. However, in reality, in her next attempt she might "fail" at the point of egg retrieval, the first step.

[27] Formalized support groups are available in some hospitals to assist women who are coming to terms with infertility, however, no support groups for women participating in IVF programmes or donor insemination programmes were reported.

[28] This information was provided by Ann McGlone Rankin, a graduate student studying the experience of women undergoing IVF.

[29] Diethylstibestrol is an artificial estrogen used to prevent miscarriage in pregnant women from 1940-1971 which resulted in second and potentially third generation cancer of daughters and sons.

[30] In the case of DES there was never any scientific evidence that it worked in humans in the first place (Newman, 1986:289).

programmes would be fully informed before beginning the procedure about, for example, the low success rate. Most women do not know and are surprised to learn that the success rate is so low. Again, it is important that education and support be provided for women making decisions about new reproductive technologies. Secondly, informed consent may be a necessary but not sufficient condition for decision-making concerning what amount to experimental procedures. Dr. Christine Overall suggests that since "some people will consent to anything" [31] that informed consent is not a sufficient condition for ethical practice and that further regulation is required. I interviewed a couple who were hiring a surrogate to carry their own genetic child (if all the procedures were successful). Since this form of embryo transfer and pre-conception contract is even more experimental than IVF when the couple use their own gametes, the success rate is even lower. At the time of the interview (June, 1987) there had been only one reported successful procedure in the world of this kind. Nevertheless, this couple was determined to try. They had been told that their chances of success were less than 5%. They were not wealthy and had re-mortgaged their home to get the $50,000.00 it would cost them to pay for the procedure.[32]

Commercialization of Reproductive Capacities: Sperm "donors" (which some argue should be called sperm "vendors") receive between $25.00 to $50.00 per donation. It is argued that this is reimbursement for time and expenses rather than payment. Since the amount is so small it may not seem significant although even this seemingly minimal reimbursement would be meaningful for someone in need of money, for example, a student or someone unemployed. The amount, however, is less significant than the precedent. Money is being exchanged to obtain the reproductive capacities of another human being. Canada does not buy or sell blood and it is documented that in countries where blood is bought and sold the quality of the blood is lower (Titmuss, 1970). The analogy between blood and reproductive capacities, however, is incomplete since blood maintains a life and reproductive capacities create <u>new</u> life. In addition, payment for sperm becomes a precedent for payment in other procedures including pre-conception contracts to bear a child and egg donation. In the U.S., women are now paid between $500.00 to $12,000.00 for egg donations (Brozan, 1988). The amount varies according to the risk undertaken by the egg donor. If, for example, she is undergoing a laparoscopy for her own reasons, e.g. tubal ligation, then the amount is lower. If she undergoes the laparoscopy (which requires a general anesthetic for egg collection) solely to donate eggs, she is paid a higher amount. The approximate cost for a woman to bear a child for someone else is $20,000.00. Usually, $10,000.00 goes to the "surrogate", $5,000.00 in legal fees and in the U.S. approximately $5,000.00 in medical costs are generally incurred. The question of whether pre-conception contracts constitute payment for a service or a product has been debated. Since the "surrogate" is not paid $10,000.00 unless she delivers a healthy infant at the end of nine months, it would seem clear that payment is for a product--the child. If, for example, the "surrogate" were to miscarry or be requested to abort a fetus due to "abnormalities", contracts specify a significantly lesser amount to be paid--for example, $1,000.00 rather than $10,000.00.

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[31] Personal Communication.

[32] They were using U.S. facilities since this procedure is not available in Canada. Therefore travel costs were added on to their total costs.

Another danger is the movement of medical services into private settings. There is at least one private IVF clinic in Toronto already and foundations have been established to further the development of others. In addition, Toronto is the setting for Canada's first sex selection clinic which opened in the fall of 1987 in Scarborough.[33]

Family Structure: A number of issues arise in relation to alterations in family structure with the use of artificial reproduction technologies. As already mentioned, it is possible through a combination of procedures for a child conceived through artificial reproduction to have five parents--two fathers and three mothers. The two fathers consist of the potential for

- a biological father through sperm donation, and
- the father who will rear the child, or the social father.

The three mothers consist of the potential for

- a genetic mother through egg donation,
- a gestational mother who could carry the fetus but not be genetically related or involved in rearing, and
- the mother who will rear the child. All of the procedures which involve donation of gametes (egg or sperm), embryos, or pre-conception contracts will involve confusion about parental roles.

Parental roles and responsibilities have traditionally followed from genetic links.[34] The exception to this is in the case of adoption, fosterparenthood, and step-parenting. In these cases, the language used indicates that the children have more than one set of parents and legal responsibilities are clarified. Given the documented need and more recent legal right (in Ontario) of adopted children to information about their biological heritage it may be expected that children conceived through artificial reproduction (where their genetic links are separate from the family who rears them) may want information about their biological heritage as well. This would mean changes in current practice of, for example, donor insemination. In some cases sperm is mixed and it is impossible to tell who the biological father is and in many cases it is unclear whether records are kept linking donors, recipients, and offspring. In Sweden, a law was passed in 1985 which required sperm donors to put information about themselves on file to which their biological offspring could have access at age 18. Despite the medical profession's fear that donors would disappear if their anonymity was not permanently ensured, this was not the case. There was a drop in availability of donors for a few months and then the numbers rose back to their original level.

Ensuring that offspring through artificial reproduction will have access to information about their genetic heritage will require records to be kept not only for linkage between participants but also so that donors could update their file about medical information (and

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[33] See Connie Clement, "Sex Selection Services," Healthsharing, Winter, 1987, p. 7.

[34] Or, more precisely, this has been perceived to be the norm in modern Western society.

potentially personal information). A donor, for example, could develop diabetes later in life and want to inform his or her biological offspring of this development. Genetic histories are increasingly important given the rise in genetic counselling and increased information about genetic disposition to certain diseases. The possibility of a centralized registry is particularly feasible through computer technology. This would also assist physicians in keeping track of how many children have been conceived through one donor and facilitate follow-up if problems arose later in the child's development or the donors'.

Others to be considered in terms of family structure are siblings, half-siblings, aunts, uncles, grandparents and spouses of gamete donors. Since the possibilities in terms of diversity of family structure are innumerable they will not be detailed here. However, the following are a few questions which will arise:

- What are the feelings of the wife or partner of a sperm donor in relation to his sperm donations and the potential children he has fathered?
- My doctoral research indicated that a substantial portion of women were not indifferent to the idea that their husband potentially had biological offspring and some of the donors had kept their donations secret from their partners. It is possible that parents as well as brothers and sisters of gamete donors may be interested or have feelings about the possible existence of biologically-related offspring.
- If a woman who agrees to bear a child for someone else has children of her own that she is rearing (as Mary Beth Whitehead did) they may be affected by witnessing their mother carry, birth, and give away a child who is their half-sibling.

These are complicated questions and it will take a very long time to find answers since there is very little research in the area and long-term follow up studies have yet to be undertaken.

Medicalization: Medical intervention in the reproductive process is a fact of modern society. Medical assistance is sought from the beginning of pregnancy and in some instances pre-pregnancy counselling is sought and provided. Increasingly, couples seek genetic counselling prior to attempting to achieve pregnancy in order to determine whether genetic predispositions to certain diseases exist. The distinction between prior medical intervention in the reproductive process and that which is possible through artificial reproduction is that the medical profession can now determine who will or will not become parents by choosing who will have access to the technologies. Deciding who is eligible to become a parent is not a project for which physicians are trained, however, they are put in (or assume) the position of making these decisions through the introduction of these technologies. This is true both in terms of who is considered to be an eligible recipient of a procedure such as donor insemination or in vitro fertilization and also whose gametes are used in cases of gamete donation. For example, in the usual practice of donor insemination

the physician, or someone other than the mother, chooses who will be the biological father of a woman's child. The sperm donor is usually matched to the physical characteristics of the woman's partner or to the woman herself. Both the choosing of the donor and the

recipient have potential eugenic implications. This is also true with in vitro fertilization where there may be a bias towards those who can afford the procedure. The possibility also exists that sperm, eggs, or embryos will be chosen because they are believed to have the certain capacities or qualities that are more socially valued than others. In sum, tremendous control is being granted to the medical profession over the process of reproduction. This is explored further in Section IV in the recommendations of the Ontario Law Reform Commission Report (1985).

III. PRENATAL DIAGNOSIS

> Prenatal diagnosis obviously raises ethical issues. Its fundamental aim is to provide information on whether a fetus is normal or abnormal. An underlying assumption is that we know how to define a defective individual or a life not worth living. (Science Council of Canada, p. 20)

Prenatal diagnosis refers to medical procedures used to obtain information about the fetus before birth. The most common ones include ultrasound, amniocentesis, and alpha fetaprotein testing. Several issues in the field of prenatal diagnosis draw attention to the importance of developments in this area in relation to the status of women. Most prominently, these include (but are not restricted to):

- the expansion of already existing prenatal diagnostic procedures to wider populations of women,
- developments (both new and old) in the technology itself which alter the relationship of a woman to her pregnancy and to the fetus she carries, and
- the unknown safety of even the most commonly used and oldest prenatal diagnostic techniques such as ultrasound.

At first glance, prenatal diagnostic techniques would seem to be quite benign compared to the some of the technologies described in the previous section on artificial reproduction. These are less sensational procedures which are not involved in the creation of new life but are used to monitor, assess, and evaluate the "normality" of fetal development. The potential implications of prenatal diagnostic procedures are perhaps more subtle since their introduction into the "management" of pregnancy does not appear with the splash of, for example, in vitro fertilization. However, the fact that their use affects every pregnant woman means that more women will directly confront an altered form of decision-making arising from these procedures. In addition, the nature of this decision-making is becoming increasingly complex given the rapid growth in this field.

A. Description of the Procedures

Ultrasound: Ultrasound is the most common and widely used of prenatal tests. The technology was originally developed to detect submarines by the Navy. First introduced in the 1960's as a safe alternative to x-rays, within a decade, ultrasound had become a standard part of obstetrical practice (Patychuck, 1985). Ultrasound for prenatal diagnosis involves high frequency sound waves projected into the uterus. The sound waves bounce back and produce echoes which can be recorded and measured. An image of the fetus is portrayed on a television-like screen. Most pregnant women, particularly in urbanized areas with major teaching hospitals, will undergo two ultrasound examinations per pregnancy (Lippman, 1986a). The most common reasons for using ultrasound include: "dating" (i.e. to see how far along the pregnancy is) to see the position of the baby, to determine if there is a multiple pregnancy or an ectopic pregnancy, and/or to find the position of the placenta (Coalition for the Medical Rights of Women, 1986, p. 9.). Ultrasound can also be used to detect neural tube defects, cleft lip, limb shortening, and fetal sex (Lippman, 1986a). Routine use of ultrasound is not, however, recommended by a variety of public health and professional organizations, including: The Society of Obstetrics and Gynecologists of Canada, International Childbirth Education Association, and the Environmental Health Directorate of the Health Protection Branch in Ottawa (Patychuck, 1985). Although ultrasound is a valuable diagnostic tool, its use has expanded beyond clinical indications. No short-term effects have as yet been detected, but concern still exists about the long-term effects of ultrasound. Evidence about the latter will not be available until second generation studies are possible, i.e. when the infants (once fetus' in utero) become adults.

Amniocentesis: Amniocentesis is used during the 15th to the 19th week of pregnancy--a period in which there is enough amniotic fluid to conduct the test. It is an excellent illustration of how prenatal diagnostic techniques overlap and compound each other. Ultrasound is employed first to determine the position of the fetus and the placenta and therefore the best place to remove the fluid. A local anesthetic on the pregnant woman's abdomen may be used to numb the area against the penetration of the long needle used to withdraw a small sample of the amniotic fluid. The fetal cells present in the fluid are grown and analyzed in the laboratory (Coaltion for the Medical Rights of Women, 1986, p. 17). The results from the test take about three to four weeks to obtain. Consequently, if a fetus is determined to be abnormal, and if the pregnant woman decides to abort, the abortion will likely occur about halfway through the pregnancy, in the twentieth week.

Amniocentesis has a history of about fifteen years. Moreover, its ability to determine fetal abnormalities continues to expand along with other medical advances in information about tissue culture, biochemistry, etc. Currently, amniocentesis can identify the sex of the fetus and diagnose "all recognizable chromosome disorders, over one hundred biochemical disorders, and many selected developmental malformations..." (Lippman, 1986a:434). The most common birth defects that amniocentesis is used for are: down syndrome (Trisomy 21), neural tube defects,[35] tay sachs, sickle cell anemia, haemophilia, and muscular dystrophy. Lippman (1986a) estimates that about 7500 women in Canada have

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[35] Neural tube defects include anencephaly and spina bifida.

amniocentesis each year. Approximately, 90% of these women are over 35 and are being screened for chromosomal abnormalities--especially trisomy 21. Amniocentesis is available in Canada to women who are known carriers of certain genetic disorders or are 35 years of age and over. At 35 the risk of abortion from amniocentesis is 1 in 200 which matches exactly the risk of finding an abnormality. The age of the biological father is also an important factor although this is not widely acknowledged.

Chorionic villi sampling (CVS): CVS is a more recent method of detecting fetal abnormality. Reports of its use in China to determine fetal sex appeared as early as 1975 but evidence of its use did not appear in Western literature until the early 1980's Lippman, 1986a). The primary advantage of chorionic villi sampling is that it can be undertaken between the 8th and the 11th week of pregnancy. Results are also available within a few days. Therefore, the decision-making process about the special needs of the child or an abortion can be made earlier in the pregnancy. Similar to amniocentesis, CVS is a procedure that will be used most commonly by women 35 and older, couples with a history of a genetic disorder, or parents who have had a child with a genetic abnormality. Chorionic villi sampling does not require an anesthetic but does, like amniocentesis, use ultrasound to guide a catheter through the vaginal canal and the cervix. A small amount of tissue (chorion) is removed through biopsy or suction. The chorion later develops into the placenta and has the same genetic make-up as the baby will later. Any chromosomal or biochemical disorders therefore can, theoretically, be diagnosed through analysis of the chorion. In Canada, chorion villi sampling is currently not available to anyone who might choose the procedure. Before the procedure is made widely available it is being studied in rigorous, controlled, randomized trials of its safety and accuracy (Lippman, 1985).

Alpha Fetoprotein Screening Test (AFP): Malformations of the neural tube (e.g. anencephaly and spina bifida) are among the most common birth defects. In some cases, these kinds of defects can be potentially predicted through the detection of an increase in a substance called alpha fetoprotein in the mother's blood level. The best time for the test is between the 16th and 18th week of pregnancy. Test results are available in approximately 1-2 weeks. The test itself, therefore, is no more invasive than a simple blood test. However, AFP testing is fraught with problems. Since it cannot really detect the existence of a defect, it is used to indicate the need for further testing (ultrasound, amniocentesis) and counselling so that the mother will understand the procedures and the risks involved. AFP testing is more accurately described as a screening procedure which indicates high or low blood levels of alpha fetoprotein thereby indicating the need for further testing. The following is a summary of a flow chart indicating the predicted results for women with high AFP levels. Out of 1,000 women tested approximately 50 will have high readings. These 50 women will all be given a second blood test. Of these 50, 30 will probably test high a second time. All of these 30 women will be sent for an ultrasound scan--7 of these will be diagnosed as normal, 5-6 will be diagnosed as having multiple births, and 18 will undergo amniocentesis for further testing. Of these 18, 16 will be diagnosed as normal, and 1-2 will be diagnosed as having neural tube defects. Thus, out of 1,000 women initially tested, 1-2 will be diagnosed as having the tested for defect (Summary from the Coalition for Medical Rights of Women, 1986, p.29). Any consideration of the utility of this testing procedure must take into account the psychological cost to the women tested who do not have defects as well as the benefits of detecting defects for women who do not wish to

bear a disabled child. Of the 1-2 who are diagnosed as carrying fetus's with neural tube defects, it is not clear what their decision may be concerning bearing or aborting the fetus carrying such a defect. In California, a voluntary mass prenatal screening program has recently been introduced which involves alpha fetoprotein testing (Steinbrook, 1986). In Canada, Lippman (1986a) reports that a similar program has been introduced in Manitoba.

B. Discussion

Prenatal diagnostic procedures are valuable tools for providing information about the fetus before birth. There are a variety of problems, however, raised by both:

- how the procedures are used, and,
- their safety. The following is a chronicling of some of the issues and questions raised in the area of prenatal diagnosis.

No attempt is made to list these issues in order of importance. Rather, what is presented is the complex of dilemmas which are,in some instances, interrelated.

1. The most powerful appeal of prenatal diagnostic procedures is ***our individual and collective desire to have healthy children***. Prenatal diagnostic procedures, however, do not eliminate disability. We can diagnose but we cannot cure or treat the majority of defects that can be detected. Presently, there are no treatments for most of the conditions that can be diagnosed before birth and none at all for chromosomal abnormalities or other genetic problems (Henifin, Hubbard, and Norsigian, 1987). Low birth weight and prematurity are the major causes of infant morbidity and mortality. These are social not medical or technical problems. They are associated with poverty, inadequate prenatal care and malnutrition, not genetic disorder. If massive prenatal screening was replaced with or accompanied by economic and social supports infant health would benefit accordingly. Similar to the issues raised in the previous section on artificial reproduction, resources could be allocated towards more preventative measures.

   Most disabilities are, however, acquired throughout life and are not congenital, therefore, disabilities will always exist in a certain percentage of the population who experience mishaps and accidents.

2. Despite many recent advances, the information provided by ***most prenatal diagnostic procedures remains ambiguous in most instances***. Consequently, the difficult social and individual issue of what constitutes the border between normal and abnormal becomes even more vexing in many prenatal diagnoses. For example, in fetuses diagnosed as having spina bifida, the neural tube fails to close properly and high alpha fetoprotein levels may be detected in the mother's blood. As discussed above, however, high levels of alpha fetoprotein do not necessarily indicate the existence of spina bifida but only the need for further testing. Uncertainty about the reasons for abnormalities in amniotic fluid can also occur during amniocentesis. Thus, a pregnant woman may

receive a positive diagnosis where no abnormal condition exists. In fact, this works both ways--both false positive and false negative results are possible. To complicate matters further, many conditions vary in severity, and many tests can determine only the existence of a disorder but not how serious it is. The rather black/white scenario of a couple who have watched one child suffer and die from, for example, Tay Sachs disease, and are able to undertake another pregnancy thanks to prenatal diagnostic techniques is actually a rare occurrence (Lippman, 1987). The decision-making process in most cases is not clear-cut but complicated by a number of factors, risks, and probabilities. These decisions must be made by the individual women involved and their partners in concert with genetic counsellors or physicians who attempt to provide as much information as possible about the consequences of the decision. As Katz Rothman (1987) points out, however, the meaning of pregnancy loss is central to understanding the consequences of prenatal diagnostic procedures. The decision to abort a wanted pregnancy is quite a different project from the issues around abortion that have been traditionally addressed by feminists. The literature on prenatal diagnosis frequently suggests the need for self-help groups for women undergoing prenatal diagnosis procedures. For women using amniocentesis, self-help groups may be particularly important given the extensive waiting period for results which concentrates the potential decision to abort into the later stages of the pregnancy.

3. ***Safety issues,*** as mentioned above, are still unresolved for most prenatal diagnostic techniques. AFP testing, a simple blood test poses no safety risks, but for women testing high it will mean further testing with technologies for which long term effects have yet to be determined. Ultrasound, for example, is described in a Metropolitan Toronto District Health Council Report (1985:23) as "having no demonstrated serious adverse effects on human beings. However, this diagnostic technique has not been in use long enough for scientists to study all the possible second generation health risks to human beings." Despite the fact that the "International Childbirth Education Association (1983), the Society of Obstetricians and Gynaecologists of Canada, and Health and Welfare Canada (1984) caution that this diagnostic technique should be used only when there is a well documented medical indication....*most physicians in Metropolitan Toronto would be hesitant not to order this procedure today in case an important diagnosis is missed*" (My emphasis, Metro Toronto District Health Council Report, 1985:24).

   Amniocentesis is a young procedure with a history of about fifteen years. It is associated with some risk of fetal loss or infant mortality. The fetal loss rate following amniocentesis is 4-5% compared to the natural risk of 2-3% (Canadian Society of Obstetricians and Gynaecologists, 1983). Finnegan et al. (1984a; 1984b; 1985) found an increase at birth of in respiratory difficulties and orthopaedic abnormalities in infants whose mothers had had amniocentesis. Her research (at Sick Children's Hospital, in Toronto) is exploratory but she suggests that the correlation may be related to the loss in amniotic fluid. This fluid is required for uterine expansion, necessary for both adequate lung development and unimpaired development of the fetal limbs. In a follow-up study at six months of infants who had undergone amniocentesis, she found several needle marks but no influence on infant mental and motor development, temperament, physical growth or the risk of orthopaedic abnormalities.

According to Patychuk (1987) concerns about chorionic villi sampling (CVS) include: false positive diagnoses, increased risk of miscarriage, introduction of infection into the uterus, fetal growth retardation and the risk of exposing the fetus to an unusually large amount of ultrasound early in pregnancy. Its use as a screening tool is also questioned since it is possible that the vast majority of fetuses may miscarry spontaneously later in the pregnancy in any case.

4. One possible argument in favour of all prenatal diagnostic procedures is that they increase women's ***reproductive autonomy*** giving women more choice over reproductive matters. To some extent this is true. At present, it is only the pregnant woman who can decide whether or not to undergo tests and what, if any, action to take as a result of the tests. Henifin, et al. (1987), however, document that this choice could also be removed and that women could be penalized for not undergoing genetic screening and/or not agreeing to an abortion if the results indicate a genetic disorder:

> Some legal commentators do not think that a pregnant woman has the right to refuse prenatal diagnosis or the right to carry a pregnancy to term if she knows that the fetus has a genetic defect. They argue that the pregnant woman should be held legally liable for refusing genetic screening if her fetus is at risk of a genetic disease. For example, the physician and jurist Marjory Shaw has stated that a woman who decides 'to carry a genetically defective fetus to term' should incur liability for 'negligent fetal abuse.'(Henifin et al. p. 8).

Several commentators have suggested that the very existence of the procedures and testing presumes that a woman will abort a fetus with a disorder--otherwise why would she undergo the test. But, it is possible that a pregnant woman would undergo prenatal testing in order to prepare for any special needs her baby may have.

As well as the possibility of pregnant women being held liable for not undergoing prenatal testing, the other side of the coin is what is referred to as calls "defensive" medicine. Physicians, in other words, may overtest to protect themselves from malpractice suits. Amniocentesis, for example, is presently considered to be standard medical practice for women 35 years and over at the time of delivery. A physician who did not at least inform a pregnant woman in this age bracket of the procedure would likely be liable for a malpractice suit.

The model of "choice" or "reproductive autonomy", however, poses a number of problems in relation to prenatal diagnosis since "choice" itself is open to abuse. Consensus on reproductive matters are not easily, if ever, achieved on a social scale. Consequently, leaving these decisions to the individual woman's choice has so far (although tenuously) proved to be the best solution. However, the process of individual decision-making now exists in a new context. Can, should, or will women abort a fetus because it is not the sex of her preference? Or, if it has a minor disorder such as a cleft palate, or slight shortening of a limb? On the other hand, aborting a fetus of a particular sex may occur to avoid the transmission of sex-specific diseases. These are difficult dilemmas and will not be resolved

easily or quickly. Among the most crucial tasks is the monitoring of choice so that it does not become subject to duty, obligation, or coercion. Having choice, as Barbara 3Katz Rothman (1987) reminds us, does not mean having control. Authentic choice could only exist in a society which did not devalue the disabled as our culture does.

5. Among the social values which lie behind the development of prenatal diagnostic techniques is what is referred to as a ***"technological imperative"***. The technology exists--therefore we should use it. In concert with this assumption is the presumption that if fetal abnormalities, particularly of the more severe type, are detected then the pregnant woman should terminate the pregnancy. To do otherwise, as mentioned above, would appear to some to be socially irresponsible. The belief system underlying the development of the technology and the assumption that all pregnant women would abort a "defective" fetus is that no one would knowingly and willingly have a child with a disability.

   The discussion so far has emphasized the fact that prenatal diagnostic techniques will not eliminate disabilities in the future. However, they do, as several writers have pointed out, have a very strong impact on the lives of disabled individuals in the present. Activists in the disabled rights movement have pointed out that screening or aborting for "defects" further devalues individuals considered by society to be "defective" (Finger,1984; Saxton, 1984). Prenatal diagnostic procedures, in fact, have the potential to further already existing stigmatization of disabled individuals. This occurs through the development of technologies which would prevent their existence reflecting the social valuing of "perfect" children and "perfect" individuals. In the future, these trends could influence the perceived needs for support services for the disabled, the need for advocacy around disabled rights, and encourage the view that the problems that the disabled encounter in our society are medical and physical, not social. It would influence the current growing trend to accommodate our environment for those who are disabled. Eugenics, the practice of selective breeding, has had social support and initiative in the past century on this continent and it is possible that a revival of this movement could occur through the availability of prenatal diagnostic procedures.

   These are some of the major issues which the use of prenatal diagnostic procedures raise. There are numerous other dilemmas, trends, and questions which surface as a result of the use of these technologies. Some of these merge with issues raised in the previous section on artificial reproduction such as the further medical management and control of pregnancy, the view of pregnancy as a disease (now with two patients--the mother and the fetus), the constant expansion of diagnostic procedures beyond their initial clinical indications, the altered relationship of the pregnant woman to her baby, the issue of genetic counselling and to what extent women are fully informed about what the diagnosis and the potential disability mean. In sum, a fundamental social impulse behind the development of these techniques is the attempt to eliminate uncertainty about the health of a developing fetus. It is not clear, however, that prenatal diagnosis does in fact improve pregnancy outcome.

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V. OTHER RESOURCES

A. Researchers:

Somer Brodribb, Doctoral Candidate, Department of Sociology, Ontario Institute For Studies in Education. Area of Specialization: Surrogate Motherhood.

Dr. Margrit Eichler, Department of Sociology, Ontario Institute for Studies in Education, Toronto. Area of unSpecialization: Pre-conception Contracts.

Nina Josefowitz, Psychologist. Toronto. Area of Specialization: Infertility.

Professor Abby Lippman, Centre for Human Genetics and the Department of Epidemiology and Biostatistics, University of McGill. Area of Specialization: Prenatal Diagnosis.

Dr. Christine Overall, Department of Philosophy, Queen's University, Kingston. Area of Specialization: Ethical and Policy Issues concerning reproduction and new reproductive technologies.

Ann Pappert, Free-lance Writer. Toronto. Area of Specialization: In Vitro Fertilization and embryo research.

Diane Patychuk: M.A., R.N., Research Assistant, College of Nurses of Ontario. Toronto. Area of Specialization: Ultrasound.

Anne McGlone Rankin, Doctoral Candidate, Ontario Institute for Studies in Education, Toronto. Area of Specialization: Infertility and the experience of women in In Vitro Fertilization.

Professor Sanda Rodgers, Faculty of Law, University of Ottawa, Ottawa. Area of Specialization: Maternal and Fetal Rights.

Mary Margaret Steckle, R.N., Patient's Right's Association, Board Member. 53 Claxton Blvd. Toronto, Phone: 653-3648. Area of Specialization: In Vitro Fertilization.

Charlynn Toews, Manitoba Advisory Council on the Status of Women.

Professor Linda Williams, Department of Sociology, Trent University, Peterborough. Area of Specialization: In Vitro Fertilization.

B. Groups

Canadian

Infertility: Facts and Feelings. A community-based self-help group of infertile men and women. Address: 639 Petrolia Road, North York, Ontario, M3J 2X8.

Reproductive Alternatives. A lobby group established in British Columbia to lobby the government to examine social policy issues around artificial reproduction.
Contact Person: Shirley Pratten, 2621 Rosstown Road, Nanaimo, British Columbia. V9T 3S2. Phone: 1-604-758-0074.

Canadian Coalition for a Royal Commission on New Reproductive Technologies. A national coaliton established to lobby the federal government to establish a Royal Commission to investigate the social implications of new reproductive technologies.
Contact Person: Margrit Eichler, c/o The Department of Sociology, The Ontario Institute for Studies in Education, 252 Bloor Street West, Toronto. M5S 1V6.

International

FINNRAGE. Feminist International Network of Resistance to Reproductive and Genetic Engineering. Canadian Contact: Louise Vandelac, Department of Sociology, University of Quebec at Montreal, Montreal, Quebec and Somer Brodribb, Department of Sociology, Ontario Institute for Studies in Education, 252 Bloor Street West, Toronto, Ontario. M5S 2V6.

"Reproductive Laws for the 1990's." Women's Rights Litigation Clinic. S.I. Newhouse Centre for Law and Justice. 15 Washington Street, Newark, New Jersey. U.S.A. 07102-3192. An information bank on research on reproductive technology--they will eventually publish a handbook and academic text (planned for this year).

"Women's Rights and Roles and Reproductive Technologies". UNESCO and World Federation of Mental Health Project. Contact Person: Professor L.F. Newman, Box G. Community Health, Brown University, Providence, Rhode Island, U.S.A. 02912.

VI. APPENDIX A.

from Pappert (1988b).

VI. APPENDIX A.

THE RECORD OF 12 CANADIAN CLINICS

CLINIC (YEAR OPENED)	COUPLES OR ATTEMPTS	PREGNANCIES	BABIES	MULTIPLE BIRTHS	SUCCESS RATE QUOTED	MOST OPTIMISTIC SUCCESS RATE BASED ON BIRTHS
Shaugnessy Hospital in Vancouver (1982)	268 couples	54	37	8	20%	11%
Foothills Hospital in Calagary (1984)	441 attempts	70	43	6	22-27%	8%
Winnipeg Health Sciences Centre (1987)	not available	not available	1	0	none quoted	--
University Hospital in London (1984)	578 couples	171	108	19 twins 7 triplets	20-25%	13%
Toronto General Hospital (1983)	308 couples	71	39	9	20%	10%
Toronto East General Hospital (1983)	1100 couples	will not release	120	21 twins 6 triplets	30%	8%
Toronto Fertility and Sterility Institute (1986)	will not release	2	0	0	20-25%	0%
Maisonneuve-Rosemont Hospital in Montreal (1986)	will not release	will not release	1	0	20%	--
St. Luc Hospital in Montreal (1986)	will not release	1	1	0	none quoted	--
Laval University Hospital in Quebec City (1979)	350 couples	not available	16	0	none quoted	5%
Grace Hospital in Halifax (1985)	78 couples	6	2	0	none quoted	3%
Chedoke-McMaster Hospital in Hamilton (1985)	250 couples	22	17	4 twins	10% quoted as a pregnancy rate	5%

Figures to the end of 1987